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Fall 2008

Issue 3

The Thread Report

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Did You Know?

- A new case is diagnosed almost every 20 minutes
- More children will be diagnosed with autism this year than with AIDS, diabetes & cancer combined
- Autism is the fastest-growing serious developmental disability in the U.S.

Thread Mom Shines at Parent Advocacy

A mother of a nine-year old daughter with autism complained bitterly. "We were at the store and Susan wasn't even acting up. Sure she was wearing her earphones but she was not misbehaving. Yet this woman stared at us. She just kept staring at us which made me feel really uncomfortable!" This mother was clearly feeling a sense of helplessness and anger. That she could even take her daughter to the store without incident was a victory. Yet she felt robbed of that victory by a stranger's stare. Every parent has suffered a similar experience. What can be done about this?

The answer is simple. Become a parent advocate. That means take everything you learn as you navigate through the bewildering reality of early intervention,

special education, ABA therapy, speech therapy, occupational therapy...and use that knowledge to advocate for your child. This often means educating the people around you.

Anu Raghuraman, whose son attends The Uncommon Thread, spearheaded a comprehensive educational program in the Hillsborough school district to increase awareness of autism and the plight of the special needs child. She was joined by law enforcement and township officials who estimate that there are over 1000 special needs children in the township.

"As more high functioning children with autism are mainstreamed," said Raghuraman, "there is a need to raise awareness of the disorder and acceptance of

these kids. I believe all schools should have an awareness program."

Mainstreaming children with autism has become more prevalent since research demonstrates that intensive behavioral therapy provided in the formative years can ameliorate the symptoms of the disease to the point where they can lead independent and productive lives. Current research suggests that 50 percent of children diagnosed with autism can make this kind of behavioral recovery even though there is no cure for autism.

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TUT Welcomes a New Program Director & Therapist

"New Program Director Emily Bellovin-O'Neill is a Board Certified Behavior Analyst which is the top designation in the ABA field. Her addition to our staff brings an expertise that will be exponentially beneficial to our students said Greg Carr, founder. "We are delighted to welcome her and look forward to the improvements in our programming that

her experience and knowledge will naturally engender."

Bellovin-O'Neill attended Rutgers University in New Brunswick, where she obtained a B.A. in Psychology. She also attended New Jersey City University in Jersey City, earning a Masters of Arts degree in Special Education and her Teacher of the Handi-

capp Certification. With over eight years of experience working with

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Emily Bellovin-O'Neill

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Shadowing Services Go To Camp

To have a child attend a main-stream camp with his fellow peers can seem like only a dream to parents dealing with autism. Here at The Uncommon Thread, this dream can become a reality through shadowing.

Shadowing is assisting a child who is preparing to enter into an environment with typical functioning peers. A shadow follows the child in order to keep watch over his or her behavior and assist the child in engaging in age-appropriate activity.

For two weeks in June, Uncommon Thread staffer Casey Carr-Jones shadowed a five year old boy, James*, at a YMCA camp. He was placed in a preschool/ kindergarten-aged group. Carr-Jones blended in with the YMCA camp counselors while always keeping one eye on James. She attended training sessions with other summer camp counselors prior to attending with James in order to become familiar with camp routines. This training enabled her to provide smoother transitions from activity to activity for "her" camper.

Camp was scheduled into four

parts: arts and crafts, sports and games, swimming, and lunch. "James participated at an age-appropriate level during arts and crafts until he was told to write his name on his project. This led to a complete melt down," said Carr-Jones. "In the two weeks that followed, I discovered that he simply liked the letter 'P' better, so as long as I wrote 'P James,' he was happy.

"During sports and games I intervened to manage occasional behaviors of running away and non-compliance," she said. One of the major complications with autism is isolation and an inhibition to socialization. During this two-week experience James began peer conversations for the first time in his life. James's counselor, Ting Chiu, said, "James has definitely improved, and much of it I think has to do with the socialization happening between him and other children in the group."

Following his week with his shadow, James was successful in completing another two full weeks of camp, this time without a shadow. This experience was a huge step for

him and was formative in getting ready to attend school in September.

"I really have to thank you and Melanie and everyone else at the Uncommon Thread that suggested that James was going to benefit from attending this camp and also for your help with the registration process. I feel this experience will open other doors for James, including his school district," said James's mother. "Just to let you know, he has been wearing his sneakers to Camp. The first three days it was a little difficult. He would wear them if I would give him a piece of candy, but currently he is doing well with wearing shoes every day. He has also been bringing the art and crafts home with initial P and then his name on it."

"Having James go to camp with you helped him to learn the daily routine, helped him to stay with the group, and prepared him for the following sessions. Your recommendations were also very helpful to me and I think for counselors as well, she said.

(*Name changed for privacy)

"One of the major complications with autism is isolation and an inhibition to socialization. During this two-week experience James began peer conversations for the first time in his life."
- Casey Carr-Jones



TUT Welcomes a New Program Director & Therapist

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children with autism she is a Board Certified Behavior Analyst. Emily has taught in behavior analytic programs in various public school districts and private schools. Bellovin-O'Neill is currently working on her Doctorate in Education with a focus on autism and behavior analysis.

Our new behavioral therapist, Lauren Conway, brings to The Uncommon Thread an enthusiasm and energy which will serve our stu-

dents well. She attended West Virginia University where she obtained a B.A. in Psychology. Graduating summa cum laude, she received a certificate of academic excellence from Eberly College of Arts and Sciences with emphasis on early development. Conway's internships have focused on pre-school children with autism spectrum disorders employing ABA intervention, PECS (Picture Exchange Communication System) and verbal communication skills training. She continues in post-

graduate study and research in the field. Her experience includes work programs at St. Jude's and Ronald McDonald House.



Lauren Conway



For more information about Autism go to.. www.theuncommonthread.org

Thread Mom Shines at Parent Advocacy

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Working with other parent volunteers, Raghuraman hung colorful and informative displays in school hallways, distributed reading materials and books to the school library, and worked with the computer teacher to add information on Autism to the school's website.

She also spoke with faculty members and suggested strategies for helping special needs children in the classroom, demonstrating parent advocacy at its best. Teachers were given copies of a children's booklet developed by the New Jersey Center for Outreach and Services for the Autism Community which answers questions likely to be asked by schoolchildren about autism.

"Parent advocacy is a fundamental reality for parents with special needs children," said Greg Carr, co-

founder of The Uncommon Thread with his wife, Aileen. "It is necessary to build your life around your child. That might mean that you have to drive a less expensive car or drop a club membership in order to afford all the therapies your child needs. I know many parents who have moved their families into a special needs-friendly school district," he said. "Aileen and I revised and restructured our family activities so that we could do things as a family. And more and more I hear about parents who are taking courses in how to complement and carry over school programs to home programs.

Aileen Carr, co-founder and therapist agreed. "Research has shown that parent involvement has a direct correlation with improved outcomes for children. By building your life around your child, you will

reap immeasurable rewards. The time, resources and energy you invest today will pave the road to independence for your child tomorrow," she said. "By learning all you can about the therapies that help your child you will have an opportunity to provide additional hours of intervention and save crucial resources. Take every opportunity to include your child in mainstream activities by going to the park, eating out at a restaurant, or going to the movies. Although this maybe difficult at first, exposing your child to typical children and acclimating them to typical environments will pay dividends far into the future."

"It isn't easy and the burden is unfair," Greg Carr said. "But I guarantee you that as you become a stronger advocate you will be able to better deal with a stranger's stare."

TUT Sponsors Bucknell Public Interest Program Intern

The BPIP Internship Fund provided The Uncommon Thread with a summer intern, Casey Carr-Jones. The Fund provided financial support for the Bucknell University undergraduate to spend her summer as an ABA assistant therapist, a summer camp shadow, and an event organizer for The Thread. Her work at TUT enabled her to gain valuable experience in both administrative and therapeutic roles.

Launched as a pilot program in 2001, the Bucknell Public Interest Program (BPIP) consists of Bucknell alumni, faculty, and administrators working together to introduce students to the field of non-profit organizations. The Fund provides opportunities for students to work in the non-profit sector. A highly selective group of BPIP grant winners are awarded an honorarium to support their summer non-profit internship.

Peter J. and Marta Hall funded The Uncommon Thread internship program this year.



Casey Carr-Jones

From the Therapist's Desk



As the new kid on the block I have been fascinated by the program here at The Uncommon Thread, especially the warm and personal relationships between families and therapists! The friendly home-like environment is perfect for the task at hand and I am delighted to be here.

You may be wondering why one of the first changes I recom-



mended as the new Program Director was a mandatory minimum hour requirement. I want to make sure that we maximize our intervention services for each child and the best way to do that is to have each child present for as many hours as possible. Having your child attend for one or two hours a week simply does not give us enough opportunity to maximize teaching. Increased frequency means an increased opportunity to acquire the skills taught.

Additionally, your child will have more access to small groups,

when appropriate, where he or she can practice peer skills, social interactions, and attending or paying attention in a group environment. All of these skills will make a difference in the quality of your family life today and prepare your child to be mainstreamed.

There are hundreds of research articles which say that a program of intensive behavioral therapy at an early age will provide the best results and that is our goal: to see that your child maximizes his or her potential.

- Emily Bellovin-O'Neill

2008

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From the Executive Director

The change of seasons is one of the great things about living in the northeast. The colors of autumn are already showing from unexpectedly cool August evenings. The sugar maples turn their top leaves first, taking almost two months to finally shed their radiant leaves readying for a dormant winter. We watch the spectacle and enjoy it for weeks. The seasons patiently wait their turn. We'll have summer again, but we have to wait. There is a more active kind of patience at work in

caring for children with neurological disorders such as Autism. But it requires an intensity and consistent follow through that is no less determined than the season's change. The process toward mainstreaming children is longer than an annual event. It is multiple years of focus, working on and watching for changes in behavior, reinforcing the appropriate and extinguishing the inappropriate.

The experience is daunting to most parents. Since this is the only proven path toward main-

stream outcomes, it is essential to our work here at the Thread that we support parents in maintaining a consistency at home that continually reinforces the efforts of the therapists. Celebrating successes is much like gradual changes to the sugar maples, but even longer. Patience is the way. Consistent care and treatment is the means. Consider a long term relationship supporting us as we offer the same to our families.

- Phil Carr-Jones

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